Self-compassion and trait mindfulness as protective factors of parental wellbeing when caring for a young person with type 1 diabetes.

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Introductory Chapter: Thesis Overview

Long Term Conditions (LTCs), such as diabetes, asthma and dementia, typically cannot be cured (NHS Confederation, 2012). The prevalence of LTCs in England is rising, with an estimated 30% of the population diagnosed with at least one LTC (NHS Confederation, 2012).

LTCs not only have a huge impact on the life of the person, but also on their family and carers. Carer burden and stress have been extensively researched and systematically reviewed to date (Cousino & Hazen, 2013; Etters, Goodall, & Harrison, 2008; Rigby, Gubitz, & Phillips, 2009), with research indicating that carer wellbeing can have a significant impact on the wellbeing of the person with a LTC, as well as on their ability to manage their condition (Whittemore, Jaser, Chao, Jang, & Grey, 2012).

Current recommendations, particularly following a recent systematic review by Cousino and Hazen (2013), suggest a proactive approach, focussing on what prevents or reduces carer stress, should be explored. Two psychological concepts that have increased in clinical interest in recent years are mindfulness and self-compassion (SC). Mindfulness is the ability to remain non-judgmental, whilst paying attention in a particular way in the present moment (Kabat-Zinn, 1990); whilst SC involves showing kindness to oneself, particularly in the face of personal suffering (Neff, 2003).

Whilst there has been a recent review exploring the efficacy of mindfulness-based interventions for caregivers of people with dementia (Hurley, Patterson, & Cooley, 2014), there are no reviews that explore the literature of both mindfulness and SC in carers of people with LTCs. Chapter one presents a systematic review of the quantitative literature to date, which aims to investigate the role of mindfulness and SC in carers of people with LTCs.

There is extensive evidence considering parental distress as a consequence of caring for a child with a LTC (see recent review by Cousino & Hazen, 2013). Mindfulness-based and compassion-based approaches are relatively new, transdiagnostic and evidence-based developments in the field of clinical psychology (Neff & Germer, 2013). They may be useful interventions for family members who are also caregivers. Several quantitative cross-sectional studies have explored the constructs of trait mindfulness and SC and how they relate to wellbeing (Baer, Lykins, & Peters, 2012; Hoge et al., 2013; Hollis-Walker & Colosimo, 2011; Van Dam, Sheppard, Forsyth, & Earleywine, 2011; Woodruff et al., 2013) but to date, no studies, to the author's knowledge, have explored these two concepts in relation to parents or carers of people with a LTC. As type 1 diabetes (T1D) is one of the most common LTCs in children (Kelo, Eriksson, & Eriksson 2013), and is at the forefront of current research, Chapter two is an empirical study from a positive clinical psychology perspective (for a review see Wood & Tarrier, 2010), which aims to explore trait mindfulness and SC as predictors of wellbeing in parents of young people with T1D.

This dissertation was undertaken to fulfil the research component of the Doctorate in Clinical Psychology.

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Chapter 1: Literature Review

Mindfulness and Self-Compassion in Carers of People with a Long-Term Condition: A Systematic Review[1]

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[1] Article prepared for submission to *'Mindfulness'* journal for peer review. Please see Appendix A for a copy of journal guidelines for authors.

Abstract

Background: Long-term conditions (LTCs) are increasing in prevalence in the UK. Carers of those with LTCs are at heightened risk of developing psychological difficulties. *Objectives:* This systematic review critically reviews, analyses and synthesises the literature on mindfulness and self-compassion (SC) in carers of people with a LTC. *Method:* PsycINFO, Scopus, Web of Knowledge and a handsearch of the "Mindful Research Monthly" newsletter were searched according to set inclusion criteria. *Results:* Seven studies met inclusion criteria. The review highlights that, whilst the two constructs have not been closely examined in this participant group, mindfulness, but not SC, could potentially be linked to reduced perceived stress in carers of those with LTCs. *Conclusions:* There was little conclusive evidence of the importance of mindfulness and SC in the literature. However it does support existing evidence that mindfulness-based interventions (MBIs) could be useful when considering wellbeing and reduced levels of distress in people. MBIs may be useful for carers of those with a LTC. Limitations of the studies and the review are discussed and recommendations for future research are suggested.

Key words: Carers, Parents, Long-Term Conditions, Mindfulness, Self-Compassion

Introduction

Long Term Conditions (LTCs), also known as chronic conditions or chronic illnesses, are conditions that last a year or more, and typically cannot be cured (NHS Confederation 2012). In order to be managed appropriately, they require on-going health-care, such as medication, physical therapies, psychological therapies and dietary support (NHS Confederation 2012; Nolte & McKee 2008). LTCs are not only physical conditions (e.g. cardiovascular disease), but also neurological (e.g. epilepsy) and psychological (e.g. depression). They can be relatively stable (e.g. asthma), or degenerative (e.g. dementia). In England, it is estimated that approximately 30% of the population (15.4 million people), have at least one LTC (NHS Confederation 2012), with the most prevalent of these being hypertension (7.5 million), depression (4.9 million), asthma (3.3 million) and diabetes (2.5 million; Department of Health [DoH] 2012).

Living with a LTC can have a significant impact on the person's wellbeing, quality of life (QoL), relationships, employment, personal finances, and their families' lives (DoH 2008). The increased stresses of having a LTC can result in family conflict, financial difficulties, social isolation, and fear about the future (Ray 2002; Streisand, Swift, Wickmark, Chen, & Holmes 2005). These can in turn lead to increased pressure on both the carer and person with a LTC, for example pressure to cope, as well as the perceived burden of caring that carers may experience (Ray 2002; Streisand et al. 2005).

Carers of people with long-term conditions

A carer is someone who provides a substantial amount of care, unpaid, for a family member or friend who may require support with day-to-day activities due to ill health or disability (DoH 2005). There are an estimated 6.5 million people in the UK who are considered carers; they may be a parent, son, daughter, partner, or friend (Carers UK 2012).

Carers commit a considerable amount of their time to look after someone, and often play a key role in the support or management of those with LTCs (Department of Health, Social Services and Public Safety [DHSSPS] 2012). This is particularly true when the person with a LTC is young or elderly, as they are generally more dependent on the help of others (DHSSPS 2012). Therefore it is sensible to reflect that caring for someone with a LTC over an extensive period of time may have an impact on the mental, emotional and physical health of the carer.

Carer burden and stress have been extensively researched and systematically reviewed to date (Baronet 1999; Cousino & Hazen 2013; Etters, Goodall, & Harrison 2008; Rigby, Gubitz, & Phillips 2009). Burden can be thought of as the stress that people who care for another may experience, such as dealing with changes in role, supporting the person with their condition, financial strain, and social isolation (Etters et al. 2008). A recent systematic review of stress in parents when caring for a child with a LTC found they experienced significantly higher levels of stress than parents of healthy children (Cousino & Hazen 2013). Indeed, many reviews exploring carer stress and burden with different conditions found that burden and stress remained high, even after long periods following diagnosis (Baronet 1999; Etters et al. 2008; Horton & Wallander 2001; Rigby et al. 2009).

However, there are some carers who appear to cope with this role extremely well, and may experience their caregiving in a positive and rewarding way (Haley, LaMonde, Han, Burton, & Schonwetter 2003). Researchers have defined this ability to cope in the face of challenges as resilience. Resilience is the capacity to withstand,

and ‘bear with’, crises by using one’s own strengths or protective factors – including social support, spirituality, intrapersonal factors, and coping skills (Brown, Fouche, & Coetzee 2010; Tugade & Fredrickson 2004; Walsh 2002). With increasing recognition of the potential positive impact of being in a caring role, including the role of resilience, there has recently been a shift in the literature that has encouraged the exploration of positive factors associated with caring, for example focusing on what maintains or promotes wellbeing over distress (Cousino & Hazen 2013). While there is no single agreed definition of wellbeing, there is general consensus that, as a minimum, in order to have psychological wellbeing there needs to be the presence of positive emotions (e.g. happiness), the absence of negative emotions (e.g. anxiety), and satisfaction with life (Diener 2000).

Mindfulness and self-compassion in wellbeing

Two psychological concepts that have increased in clinical interest in recent years are mindfulness and self-compassion (SC). Mindfulness is termed as the ability to remain non-judgmental, whilst paying attention in a particular way in the present moment (Kabat-Zinn 1990). It incorporates attitudes of non-judgment, a beginner’s mind (as if seeing something for the first time), trust, non-striving, acceptance, letting go and patience (Kabat-Zinn 1990); and is in contrast to a ruminative state of going over the past, planning for the future (e.g. worry), or analysing current experiences, often with attitudes of judgment or intolerance (Splevin 2012). Mindfulness applies to all experiences, being aware of the five senses, as well as the body; thoughts and feelings with a sense of approach towards experience, with curiosity and intent, rather than avoidance (Van Dam, Sheppard, Forsyth & Earleywine 2011). Some people may be naturally more mindful (trait mindfulness;

Brown & Ryan, 2003); and one would expect that someone high in trait mindfulness would be better able to tolerate a larger amount of distress without difficulty compared to someone with low trait mindfulness (Bullis, Bøe, Asnaani, & Hofmann 2014). Research suggests that by increasing trait mindfulness, through specific mindfulness training, reported stress is reduced whilst subjective wellbeing and mood increases (e.g. Baer 2003; Piet & Hougaard 2011).

SC involves showing kindness to oneself, particularly in the face of personal suffering (Neff 2003a). It is posited that there are three components to SC; kindness and understanding to oneself rather than self-criticism and judgment, seeing experiences as a whole rather than separate, and holding painful thoughts and feelings in awareness rather than interacting with them excessively (Neff 2003a). As with mindfulness, the intention is to hold an awareness of thoughts; however it also emphasizes emotional factors such as feelings of care and empathy (Woodruff et al. 2013). Research has shown that higher SC reduces the experience of negative feelings (MacBeth & Gumley 2012; Van Dam et al. 2011).

Neff (2003a) argues that mindfulness is a core component of SC, or that at least they are related and complementary constructs (Neff & Dahm in press). Both concepts have been implicated in relation to wellbeing and the ability to remain caring and self-compassionate in professional caregivers (i.e. nurses, clinical psychologists; Rimes & Wingrove 2011; Halifax 2011), with Shapiro and colleagues (2005) finding that, following a mindfulness-based stress reduction (MBSR [Kabat-Zinn 1990]) trial for health professionals, stress reduced and levels of reported SC significantly increased. Neff and Pommier (2013) studied the link between SC and compassion for others, finding those with higher reported levels of SC were less likely to experience personal distress, and therefore more able to support another who was suffering without being overwhelmed (i.e. they were better able to cope; Neff & Dahm in press).

Aim

Recent literature has reviewed how stressful it can be to cope with caring for someone with a LTC, particularly when caring for a child (Cousino & Hazen 2013); and also the potential usefulness of mindfulness as an intervention for dementia caregivers (Hurley, Patterson, & Cooley 2014). Mindfulness and SC are two psychological constructs that may be related to, and improve, psychological wellbeing, but no reviews to date (to the best of the author's knowledge) have explored these two constructs in terms of caring for someone with a LTC, or how they may act in relation to the role of the carer. The aim here, therefore, is to systematically review the literature related to mindfulness and SC in carers of people with a LTC, and to assess whether SC and mindfulness are related to carer wellbeing; as well as consider the limitations of the current literature and highlight areas for future research.

Method

Inclusion Criteria

Studies were included for review if there was a measure of mindfulness and/or SC included as part of the core battery of measures under investigation, utilised quantitative methodology only, published in English in a peer-reviewed journal, and full text articles were available. Cross-sectional, randomised controlled trials (RCTs) and longitudinal research were included. Only studies including at least one of the most prevalent LTCs, based on the DoH's compendium of LTCs, were included (Hypertension, depression, asthma, diabetes, coronary heart disease, chronic kidney disease, hypothyroidism, stroke, chronic obstructive pulmonary disease, cancer, atrial fibrillation, mental health, heart failure, epilepsy and dementia; DoH 2012).

Exclusion Criteria

Studies were excluded if any of the following criteria were met; 1) single case studies, 2) literature reviews, 3) discussion papers, 4) books, and 5) if the study included health professionals as the main carer. Literature searches were limited to exclude papers published before 1990, to coincide with the publication of the first manual of a mindfulness-based intervention (MBI) within a clinical context (MBSR; Kabat-Zinn 1990).

Information Sources

An electronic search was conducted using Web of Science (WoS), PsycINFO and Scopus databases from February to March 2014. A handsearch of an online newsletter from the website Mindful Experience, the “Mindfulness Research Monthly”, was also conducted. “Mindfulness Research Monthly” is a comprehensive record of all new publications related to mindfulness, which is updated monthly (http://www.mindfulexperience.org/newsletter.php).

Search Strategy

Predetermined keywords were used to search for relevant articles. They were: (“long-term condition*” OR “chronic condition*” OR “chronic disease*” OR “chronic illness*”) AND (carer* OR caregiver* OR parent* OR mother* OR father* OR family OR partner*) AND (mindfulness OR MBSR OR MBCT). Then (“long-term condition*” OR “chronic condition*” OR “chronic disease*” OR “chronic illness*”) AND (carer* OR caregiver* OR parent* OR mother* OR father* OR family OR partner*) AND self-compassion. These search terms were identified in the title, abstract or keyword list of journal articles on each database. The hand search of the “Mindfulness Research Monthly” newsletter was based on what the author perceived as relevant titles only (e.g. included keywords from the search strategy employed for the databases). Details of the search and inclusion criteria were specified in advance and documented in a protocol (see Appendix B).

Screening

Following the removal of duplicates, literature searching resulted in 119 papers potentially eligible for review. These 119 papers were retrieved and their abstracts screened to assess whether they met the inclusion/exclusion criteria. One hundred and one studies were excluded at this stage for: being a review, book, letter, case study or study protocol; being qualitative in design; not meeting the included LTCs criteria; not exploring mindfulness or SC; and either involved a health professional or was not carer focussed. Following this initial screening, 18 full-text articles were assessed for suitability.

Of these 18 papers, eleven were rejected because they did not have a mindfulness or SC measure included (Clark, Doyle, Walsh & Robson 2012; Danucalov et al. 2013; Lavretsky et al. 2012; Lengacher et al. 2012; Meharanfar, Younesi & Banihashem, 2012; Minor, Carlson, MacKenzie, Zemicke, & Jones 2006; Moorhead 2012; Norouzi, Golzari & Sohrabi 2014; Whitebird et al. 2011; Whitebird et al. 2013; Williams, Ness, Dixon & McCorkle 2012). The remaining seven papers form the foundation of this review. The reference lists of the seven final identified papers were also checked to identify additional studies; this produced no further papers for review. Figure 1 reports the flow diagram of the screening procedure reported, in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman 2009) guidelines.

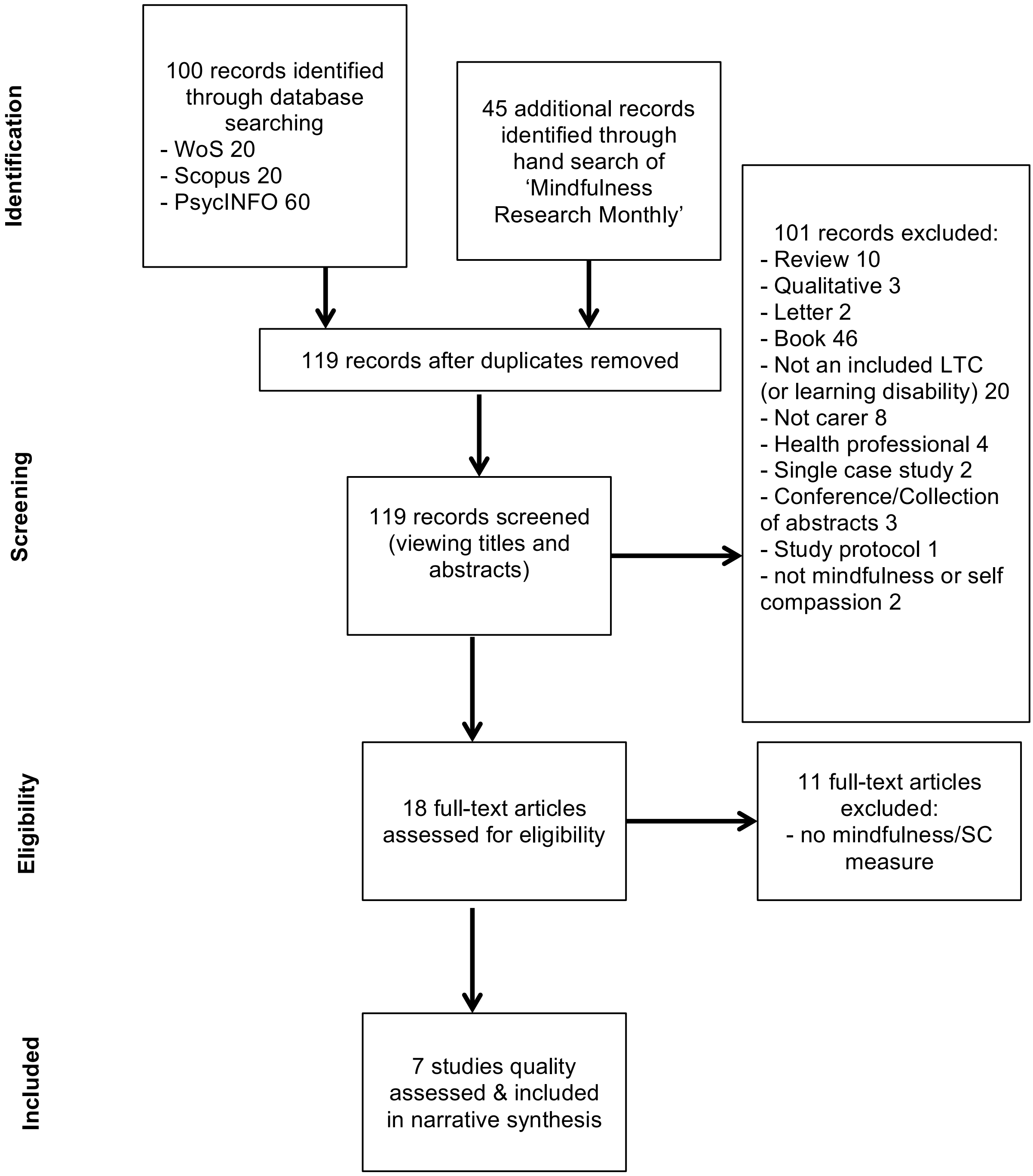

Fig. 1 Flow of information through the different phases of the systematic review, based on the PRISMA guidelines for systematic reviews

Quality Assessment

In line with the PRISMA guidelines (Moher et al. 2009), the quality of papers should be assessed when conducting a systematic review. This systematic review utilised a quality assessment tool developed by Melbourne for a previous doctoral thesis (2010), and adapted from checklists by Downs and Black (1998) and the Strengthening the Reporting of Observational studies in Epidemiology (STROBE; 2007). This checklist was chosen as the most appropriate as it had been devised to review a variety of research studies (i.e. cross-sectional and randomised controlled trial [RCT]; Melbourne 2010). The checklist is comprised of 16 items (one with three levels), with items referring to areas of study rationale, recruitment, methodology and statistical analysis. Each criteria is rated ‘yes = 1’, ‘no = 0’ or ‘not applicable’, (see Appendix C for a copy of the tool). To ensure reliability, two researchers independently quality assessed the papers.

Results

Seven studies were included in the review, relevant data were extracted (see Appendix D for extraction form), and the main details of these studies are reported in Table 1. The studies were conducted in four different countries (USA, Canada, Hong Kong, Australia), and published between 2010 and 2014.

The study sample sizes varied between nine (Epstein-Lubow et al. 2011) and 141 participants (Hou et al. 2014). Of the seven studies included in the review, one utilised a cross-sectional design (Oken, Fonareva, & Wahbeh 2011), two utilised a RCT design (Hou et al. 2014; Oken et al. 2010), and the remaining four utilised a case series design (Birnie, Garland & Carlson 2010; Epstein-Lubow et al. 2011; Hoppes, Bryce, Hellman, & Finlay 2012; Sharplin et al. 2010) in line with The

Cochrane Collaboration (2012) definition of a case series design as a study involving an intervention group with no comparison group. Four studies included carers of people with dementia (Epstein-Lubow et al. 2011; Hoppes et al. 2012; Oken et al. 2010; Oken et al. 2011), two studies explored people affected by cancer (Birnie et al. 2010; Sharplin et al. 2010), and one study explored carers of people with chronic conditions (Hou et al. 2014). No operational definition or demographics of which chronic conditions included were discussed in the article, but the authors were contacted to gather extra information (S. Y. S. Wong, personal communication, March 27, 2014) – see Table 1 for full details. Six of the seven studies evaluated a mindfulness intervention, whilst Oken and colleagues (2011) explored the effect caregiving could have on carers cognitive functioning. Two studies included both the person with the LTC and either their partner or a carer in their evaluations; both these studies were in relation to those affected by cancer (Birnie et al. 2010; Sharplin et al. 2010).

Overview of the Quality of the Included Studies

Two researchers rated each of the seven studies, with the ranking of the studies reported in Table 1, and the quality assessment domain scores reported in Table 2. Inter-rater reliability was high, with an interclass correlation coefficient (ICC) of .968. Landis and Koch (1977) reported that an acceptable inter-rater reliability score includes those with an ICC greater than .70. The quality of the reviewed studies varied, with Hoppes and colleagues' (2012) study ranked the lowest, whilst both raters agreed that Hou and colleagues (2014) study scored 100% using the checklist. Due to the heterogeneity of the studies, however, these should be interpreted with caution, as it is difficult to draw conclusions regarding the overall quality of the seven papers.

Table 1. Summary of studies under review

Author	Date	Country	LTC	Study *N*	Participants	Method	Aim	Mindfulness/SC measure	Paper Ranking
Oken et al.	2011	USA	Dementia	56	31 caregivers 25 non-caregiving controls	Cross-sectional	Evaluate the effect of dementia caregiving stress on cognitive function in older adults	MAAS Subscale from KIMS	2
Oken et al.	2010	USA	Dementia	28	28 caregivers - 8 mindfulness intervention - 11 active control (education) - 9 passive control (respite)	Pilot RCT	Evaluate whether a mindfulness meditation intervention may be effective for dementia caregivers	MAAS FFNJ	3
Hou et al.	2014	Hong Kong	Chronic Conditions*	141	70 caregivers 71 control	RCT	Evaluate the acceptability, feasibility and effectiveness of MBSR to improve mental health in Chinese caregivers of someone with chronic condition	FFMQ SCS-SF	1
Hoppes et al.	2012	USA	Dementia	11	11 caregivers	Case series design (mixed methods)	Investigate the effects of brief mindfulness on wellbeing of dementia caregivers	FMI	7
Birnie et al.	2010	Canada	Cancer	42	21 couples (cancer sufferer and their partner)	Case series design	Exploration of MBSR and its impact on stress, mood and mindfulness for patient & partner	MAAS	4
Epstein-Lubow et al.	2011	USA	Dementia and severe medical conditions	9	9 female caregivers	Case series design (mixed methods)	To see if MBSR would be acceptable to busy and distressed caregivers and if it reduced depressive symptoms and perceived burden	KIMS	6
Sharplin et al.	2010	Australia	Cancer	21	16 cancer patients 5 carers	Case series design	Evaluate an MBCT program and it's impact on depression and anxiety symptoms in people affected by cancer	FMI	5

Note. * Following contact with the corresponding author (S. Y. S. Wong, personal communication, March 27, 2014), further information about the chronic conditions was gathered, the majority (78.3%) of care recipients had more than two chronic conditions, with the most common chronic conditions being hypertension (53.2%), diabetes and heart diseases (31.9%), chronic pain (31.2%), stroke and dementia (29.1%). Abbreviations used: SC = Self-compassion; RCT = Randomized controlled trial; MBSR = Mindfulness-Based Stress Reduction; MBCT = Mindfulness-Based Cognitive Therapy; MAAS = Mindful Attention Awareness Scale; KIMS = Kentucky Inventory of Mindfulness Skills; FFNJ = Five Factor Non-Judgmental scale; FFMQ = Five Facets Mindfulness Questionnaire; SCS-SF = Self-Compassion Scale – Short Form; FMI = Freiburg Mindfulness Inventory.

Table 2. Quality assessment domain scores for studies under review

Question Domains	**Oken et al. (2011)**	**Oken et al. (2010)**	**Hou et al. (2014)**	**Hoppes et al. (2012)**	**Birnie et al. (2010)**	**Epstein-Lubow et al. (2011)**	**Sharplin et al. (2010)**
Abstract	1	1	1	1	1	1	1
Scientific Background	1	1	1	1	1	1	1
Aims and Hypotheses	1	1	1	1	1	1	1
Main Outcomes to be Measured	1	1	1	1	1	1	1
Participant Characteristics	1	1	1	1	1	1	1
Treatment	N/A	1	1	1	1	1	1
Inclusion/Exclusion Criteria	1	1	1	1	1	0	1
Representative of Population – Part 1	1	1	1	1	1	1	1
Representative of Population – Part 2	1	1	1	0	1	0	1
Proportion of those Consented	0	0	1	0	0	0	0
Characteristics of those Lost to Follow-Up	N/A	1	1	N/A	N/A	N/A	0
Main findings	1	1	1	1	1	1	1
Statistical methods	1	1	1	1	1	1	1
Statistical methods – Controlling Confounding Variables	1	0	1	N/A	0	1	1
Actual Probability Values	1	1	1	0	1	1	1
Accurate Measures	1	1	1	1	1	1	1
Limitations	1	1	1	0	1	1	1
Key Results Summary	1	1	1	1	1	1	1
Total (*out of 18, unless otherwise stated*)	*15/16*	*16*	*18*	*12/15*	*15/17*	*14/17*	*16*

Mindfulness and Self-Compassion

Two of the studies reviewed explored changes to mindfulness or SC in carers of people with LTCs as a secondary outcome, following intervention (Hoppes et al. 2012; Hou et al. 2014). All studies, apart from Oken and colleagues study (2011), investigated how effective a MBI was at reducing levels of depression, stress and perceived burden in caregivers. Oken and colleagues (2011) investigated if caring for someone with dementia impacted on cognitive functioning in the caregiver. As this review aims to establish how mindfulness and SC has been used in the literature regarding carers of people with LTCs, the synthesis of the studies will focus mostly on these constructs, and how they were explored in relation to the study outcomes. However, the primary outcomes of each study will be considered as potential mediators of change.

All seven studies included at least one measure of mindfulness. Four different mindfulness measures were used, and two individual scales from mindfulness measures; the Mindful Attention Awareness Scale (MAAS; Carlson & Brown 2005), the Kentucky Inventory of Mindfulness Skills (KIMS; Baer, Smith, & Allen 2004); the Five Facets Mindfulness Questionnaire (FFMQ; Baer, Smith, Hopkins, Krietemeyer, & Toney 2006), the Freiburg Mindfulness Inventory (FMI; Buchheld, Grossman, & Walach 2001), the *accept without judgment* subscale of the KIMS, and the *non-judgmental* facet of the FFMQ. Only one study (Hou et al 2014) included a measure of SC; the Self-Compassion Scale-Short Form (SCS-SF; Raes, Pommier, Neff, & Van Gucht 2011).

Cross-sectional study outcomes

Oken and colleagues (2011) employed the MAAS (Carlson & Brown 2005) and the *accept without judgment* subscale of the KIMS (Baer et al. 2004) when comparing dementia caregivers and non-caregiving controls on cognitive functioning tasks in a cross-sectional study. It considered the MAAS a measure of current moment mindfulness, with the subscale of the KIMS concerned with how much the participant negatively criticised their thoughts, feelings, behaviours and experiences

(Oken et al. 2011). Oken and colleagues (2011) used six other self-report measures, demographics, and salivary cortisol was measured when taking part in the cognitive functioning tasks assessing attention and executive functioning. The study found that caregivers performed worse on attention tasks than non-caregivers (p = .006, d = .606); and there were significant differences in stress and depression levels, with reported stress and depression levels higher in the caregivers group. Sleep was the only potential mediator. There was no significant difference between groups when analysing the MAAS (p = .57, d = -.142), however there was a significant difference between groups when analysing the subscale of the KIMS (p < .001, d = -1.06). The study highlighted that mindfulness was significantly correlated with neuroticism (r = -.550, p < .0005) and fatigue (r = .355, p < .05), which suggests that lower levels of trait mindfulness was associated with higher neuroticism and greater fatigue. However, the study had a number of limitations, in particular the sample size (N = 56) was small making conclusions difficult. SC was not measured in this study.

Randomised Controlled Trial study outcomes

Oken and colleagues' (2010) study report a pilot RCT with three arms (mindfulness intervention, education, and respite) exploring the effects of a MBI with dementia caregivers. The researchers used two mindfulness measures to explore whether mindfulness was a mediating factor for any improvements reported with the intervention; the MAAS (Carlson & Brown 2005), and the *non-judgmental* facet of the FFMQ (Baer et al. 2006), which they called the FFNJ. The researchers also used a large battery of outcome measures, including the primary outcome measure of the Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al. 1992), as well as ten other secondary measures measuring areas of stress, depression, and perceived sleep quality. Demographics, salivary cortisol measurements and some cognitive assessments were also completed. Participants completed measures pre- and post-intervention, with no follow-up. Following the intervention, there was found to be no differences between the mindfulness and education group on the RMBPC scores (p = .839, d = .409), with only a difference evident between the mindfulness and respite group (p = 0.041, d = -.205). However, there was no significant difference between the three groups on either of the mindfulness measures (MAAS = p .950; FFNJ = p .286). Despite this, Oken and colleagues (2010) found that levels of mindfulness were negatively correlated to both self-reported depression (r = -.688, p < .01) and perceived stress (r = -.583, p < .01), even at the pre-intervention phase. In light of this finding, the authors suggest that mindfulness is an important construct in wellbeing. However, the study appeared underpowered (N = 28), lots of measures were utilised, and there was no follow-up to determine if changes were sustained over time. SC was not measured in this study.

Hou and colleagues' (2014) conducted a RCT of a MBSR programme compared to a self-help control group. The study aimed to evaluate the acceptability, feasibility and effectiveness of MBSR with family caregivers of those with a chronic condition. This was the only study reviewed that included both a mindfulness and SC measure. They utilised 10 outcome measures, including the FFMQ (Baer et al. 2006) as a secondary outcome measure to explore if the MBSR programme had increased levels of mindfulness in carers of people with a chronic condition; and the SCS-SF (Raes et al. 2011) to explore SC. Participants completed measures at pre-, post-intervention and three-month follow-up. Hou and colleagues (2014) found that those in the MBSR group showed significantly greater reductions in depression symptoms at both post-intervention (p < .01, d = -.414) and follow-up (p < .01, d = -.358);

anxiety levels also improved after the intervention (p = .007, d = -2.839), although this was not maintained at follow-up (p = .081, d = -.239). In terms of mindfulness there was no significant differences in the levels of mindfulness between the intervention and control groups at pre-intervention (p = .234, d = .194); however three-months post-intervention found a significant difference (p = .001, d = .445) between the groups, with the intervention group showing increased levels of mindfulness. An increased level of mindfulness was also found to be correlated with reduced levels of depression, anxiety and perceived stress at follow-up (although no data was reported, or could be obtained, to support this). However no significant differences were found in SC scores between the intervention and control groups at pre (p = .056, d = .138), post (p = .265, d = .148) or follow-up (p = .202, d = .174). Hou and colleagues (2014) considered their findings to demonstrate that MBSR was an effective and acceptable intervention, based on the weekly practice log collected to review frequency and duration of home practice. The authors also recognised that whilst they had calculated power prior to the study and recruited 141 participants, they had been unable to meet the estimated sample size due to attrition. The results of this study give rise to a number of considerations. Given the existing wider literature to date consider mindfulness and SC as related constructs (Neff & Dahm, in press), the findings here are contradictory. These may be due to the measurement tools themselves, in that the SCS-SF may not be a reliable or valid measure of SC as compared to the long version (Neff 2003b), or mindfulness and SC may act in different ways when considering carers.

Case series study outcomes

The remaining four studies were case series deigns, whereby they had only an intervention group with no comparison (Birnie et al. 2010; Epstein-Lubow et al. 2011; Hoppes et al. 2012; Sharplin et al. 2010).

Hoppes and colleagues (2012) explored the effects of a brief mindfulness intervention (4 hours) on 11 family caregivers of people with dementia. It employed a mixed methods design, and specifically explored the effects on wellbeing of the caregivers, with the construct of mindfulness being part of this. Four outcome measures were used, as well as a brief interview, with mindfulness measured using the FMI (Buchheld et al. 2001). Participants completed measures at pre- and post-intervention and one-month follow-up. The study found that levels of burden reduced ($F(2,18) = 6.23$, $p < .01$; $\eta^2 = .41$) and there was a significant increase in levels of hope ($F(2,18) = 7.56$, $p < .01$; $\eta^2 = .46$). However, whilst the average scores of mindfulness increased, from 38.31 to 41.44, the differences were not statistically significant ($F(2,14) = 1.30$, $p > .05$; $\eta^2 = .16$). As with Oken and colleagues' (2010) findings, mindfulness was strongly negatively correlated with the negative factors associated with caring at post-intervention, in this case perceived burden ($r = -.69$). However, as the study used a brief mindfulness intervention and only had 11 participants it was hard to draw any firm conclusions. Interestingly, when examining the qualitative data using thematic analysis they found that participants discussed themes of increased acceptance, a sense of presence and peace, and reduced reactivity, which are in line with the current definitions of mindfulness. SC was not measured in this study.

Birnie and colleagues (2010) explored the psychological benefits of participating in an MBSR programme for cancer patients and their partners. They were the only study that specifically stated that they wanted to examine MBSR's impact on mindfulness for cancer patients and their partners, as well as stress and mood disturbance. The study used three outcome measures to look at each of the aims. The MAAS (Carlson & Brown 2005) was used to explore mindfulness. Measures were completed at pre- and post-intervention with no follow-up. Birnie and colleagues (2010) found no significant difference between the patient and their partner, suggesting that the experience of going through cancer impacts the whole family in similar ways. The study reported a significant decrease in mood disturbance ($F(1,40) = 4.49$, $p < .05$) and some of the stress subscales (for both the patient and their partner), and a significant increase between pre- and post-intervention mindfulness scores ($F(1,40) = 6.10$, $p < .05$). Effect sizes were looked at separately, and obtained using Cohen's *d.* For the patients, effect sizes were 0.35 for total mood disturbance, 0.16 for total symptoms of stress, and 0.21 for mindfulness. For partners, effect sizes were 0.34 for mood disturbance, 0.37 for symptoms of stress, and 0.50 for mindfulness. These represented small-to medium-sized effects for patients and partners. The lack of control group and the small sample size (N = 42), however, limit the generalizability of the findings. SC was not measured in this study.

Epstein-Lubow and colleagues (2011) explored an MBSR programme with nine caregivers of those described as 'frail elderly' (dementia and severe medical conditions). Their primary aim was to explore the acceptability of the programme with this participant group; this was done by utilising a mixed methods approach. The MBSR programme was adapted in order to make it more acceptable for caregivers. They utilised seven outcome measures, including a depression and anxiety scale; and mindfulness was measured using the KIMS (Baer et al. 2004).

Measures were completed pre- and post-intervention and at one month follow-up, with the depression and mindfulness measures also being completed midway through the intervention. They found that whilst depression levels reduced during the intervention (pre = 16.6 [12.9], post = 13.7 [7.4]; with an effect size of $d = .29$), they had returned to mean pre-treatment levels at follow-up (17.2 [13.2]). The authors also found no significant differences pre-, post-, or at one-month follow-up for mindfulness (no p value reported, $d = .15$); however on one of the KIMS subscales (*Act with Awareness*), a significant change was seen between pre- and post-intervention ($F(1,5) = 6.82$, $p = .048$, $\eta^2 = .58$), which Epstein-Lubow and colleagues (2011) felt demonstrated that participants acted with more awareness as the intervention progressed. The sample size, however, was extremely small ($N = 9$), and therefore no firm conclusions can be drawn about the study. SC was not measured in this study.

Finally, Sharplin and colleagues (2010) explored mindfulness-based cognitive therapy (MBCT [Segal, Williams & Teasdale 2002]) in relation to depression and anxiety symptoms in a sample of people affected by cancer (16 cancer patients and 5 carers). They collected demographics and used three outcome measures to explore depression, anxiety and mindfulness. The FMI (Buchheld et al. 2001) was used to measure mindfulness, and was a secondary outcome measure after depression and anxiety scores. The measures were completed at pre- and post-intervention and at three-month follow-up. As with Birnie and colleagues' (2010) study, Sharplin and colleagues (2010) found that there were no significant differences between the person with cancer or their carer at pre-intervention. At post-intervention they found significant improvement in depression ($F(1,24) = 6.37$, $p = .012$, $\eta^2 = .27$) and anxiety ($F(2,34) = 9.43$, $p = .001$, $\eta^2 = .36$) levels, which was maintained at follow-up. Results also demonstrated a significant change in mindfulness scores between pre-intervention and follow-up three months later ($F(2,32) = 8.36$, $p = .001$, $\eta^2 = .34$). Sharplin and colleagues (2010) also demonstrated that improved mindfulness scores were associated with decreased levels of reported depression ($r = -.46$, $p = .048$) and anxiety ($r = -.50$, $p = .029$). However, there was no control, and only a small number of carers ($n = 5$ out of total $N = 21$) were recruited to the study, which makes it difficult to generalise to all carers. SC was not measured in this study.

Discussion

This review aimed to systematically gather and synthesise literature relating to two positive psychological constructs, namely mindfulness and SC, in research relating to the wellbeing of carers of people with a LTC. Seven studies were included in the review. Within these studies, six of the seven looked at the effectiveness of a MBI. The studies used four different mindfulness measures, and only one study employed a SC measure (Hou et al. 2014). The limitations of the included studies, limitations of the review, and recommendations for clinical practice and future research are discussed in turn.

Limitations of the included studies

There are a number of limitations of the included studies that should be considered. The quality of the studies varied, with the quality assessment scores ranging from 72% (Hoppes et al. 2012) to 100% (Hou et al. 2014), which impacts on the interpretations that can be made. Although there were variations in the quality of the studies, there were also common limitations. As found in Hurley and colleagues'

(2014) review of meditation-based interventions for caregivers of people with dementia, the majority of studies reviewed here used a case series design. These are known not to be as methodologically robust as RCTs; therefore findings should be interpreted with caution (Howick et al. 2011).

Moreover, the studies may not be generalisable to similar populations due to potential recruitment biases, as identified by the researchers themselves (Oken et al. 2011; Hou et al. 2014; Epstein-Lubow et al. 2011; Sharplin et al. 2010). This is a particularly important point, as it has been recognised that caregivers are already under extreme time pressures, and are therefore generally harder to recruit to studies that require any commitment of time.

A further limitation of the included studies were the sample sizes and lack of reported power calculations. With studies varying in sample size from as little as nine, up to 141 participants, this made it difficult to determine whether enough participants were included to detect significant differences. Hou and colleagues' (2014) study was the only study to include a discussion of power.

None of the reviewed studies reported how long the person with the LTC had had the condition, or for how long the carer had spent caring. These factors have been shown to be important in how the carer perceives the burden associated with coping and caring (Etters et al. 2008; Langa et al. 2001), and it is therefore recommended that future studies gather and report this information. This is an important issue, as they could be potential mediators in how well a carer perceives they are coping. It is also important as it could determine whether early intervention at the post-diagnosis stage for the carer (and person with the LTC) would be beneficial in promoting wellbeing.

Finally, there were inconsistencies with regards to the measures used to assess mindfulness. Measures are important in order to tell if people who undertake MBIs become more mindful over time and whether this mediates the effects of mindfulness training on psychological health (Baer et al. 2008). Four different measures of mindfulness were used across the included studies. The differences in content and structure of the measures suggest a lack of consensus regarding the conceptualisation of mindfulness; and also that they may be tapping into different constructs (Baer et al. 2008). For example, the MAAS (Carlson & Brown 2005) is unidimensional, the KIMS (Baer et al. 2004) is based on Dialectical Behaviour Therapy, looking at internalised skills and is multifaceted; and the FFMQ (Baer et al. 2006) is made up of items from the KIMS, FMI (Buchheld et al. 2001), MAAS, the Cognitive and Affective Mindfulness Scale (Feldman, Hayes, Kumar, Greeson, & Laurenceau 2007) and the Mindfulness Questionnaire (Chadwick, Hember, Mead, Lilley, & Dagnan 2006). Researchers have suggested that in order to understand the skills of mindfulness, how they are cultivated in MBIs, and how they relate to psychological adjustment, then multi-faceted measures are the best measures to use (Baer et al. 2008).

Limitations of the review

Whilst the aim was to provide a high quality review, there are a number of limitations. First, as only seven studies met the criteria for inclusion (given the paucity of literature regarding mindfulness, SC and carers of those with LTCs), and the heterogeneity of the included studies, the opportunity to conduct a meta-analysis was not appropriate. However, it is important to note the shift in exploring mindfulness and SC in the wider literature (see Woodruff et al. 2013); therefore there is potential to utilise these constructs within interventions with carers. As such, it seemed timely to conduct this review to explore the potential role of mindfulness and SC for carers' psychological wellbeing. Whilst the inclusion criteria allowed for the inclusion of measures of either mindfulness or SC, only one study empirically evaluated SC (Hou et al. 2014). The results with regards to SC therefore are limited, in that the review highlighted no evidence that SC is an important construct in relation to carer wellbeing. Further exploration of the potential role of SC in MBIs and psychological health with carers of people with LTCs was therefore not possible within this review.

Second, the quality assessment tool chosen may have had some limitations. As it was designed to cover a variety of different study designs, it meant that certain important areas to consider when assessing quality were omitted, such as missing data or randomisation. As such, the quality of the papers may have been rated as higher quality than they truly were. However, it was considered an adequate tool for this exploratory review in order to give a consistent score in which to compare the studies as best as possible against each other. Future reviews may find it more helpful to use specific quality assessments tools for the different types of studies being reviewed (i.e. cross-sectional tool, or RCT tool).

Third, the review may have some publication bias, as although the author looked through a variety of sources for studies, including a hand search of the "Mindfulness Research Monthly" newsletter, the author failed to search unpublished dissertation databases nor contact researchers who may have unpublished work. It is therefore possible that important studies were unintentionally missed. Third, the definition of carer in the literature is varied. In order to try and include as many relevant studies as possible, this review looked at all research where it specifically included a carer, parent, family or partner as a participant, however some of these may have not been specifically caring for the person with the LTC – for example, the authors were unable to tell if the partners recruited to Birnie and colleagues' (2010) study also acted specifically as carers. However, a decision to include the study was made as participants were somebody close to the person with a LTC, and research indicates that family members are impacted (DoH 2008).

Finally, the definition of LTCs is debatable. Whilst the review used a working definition from the NHS Confederation (2012) and the DoH (2012), and limited the search to the most prevalent LTCs in the UK, although it is possible that some studies focussing on less prevalent LTCs, such as multiple sclerosis, may have provided useful information that could have added further to this review. It is also possible that by not searching for specific LTCs (e.g. diabetes) in the search terms may have missed some studies; however, on doing a brief search using specific LTCs it did not find any additional papers, and in fact missed some of those included in this review. Therefore, as the review was exploratory in nature and the focus was not condition specific (rather it was on the role of mindfulness and SC on the wellbeing of carers), a decision was made to use the most common ways of describing LTCs as the search terms.

Clinical implications and future research

The findings reported here indicate that participation in MBIs demonstrate improvements in caregivers' levels of stress, perceived levels of burden, and wellbeing. These findings mirror those of Hurley and colleague's (2014) recent review of meditation-based interventions for caregivers of people with dementia, and provide some evidence to suggest that MBIs could be beneficial for all caregivers of those with a LTC. It also highlights the importance for clinics supporting those with LTCs to consider the carer. Therefore it may be useful for health care professionals to consider the whole family, or system, around the person with the LTC. The lack of research of other more prevalent LTCs, such as asthma, diabetes or mental health problems, suggests that future studies should look towards these. Whilst cancer can prove to be significantly stressful for those affected by it, and those caregiving for dementia experience high levels of burden, the long-term burden of someone being diagnosed with LTCs such as a mental health problem, asthma or diabetes, could have different demands and burdens, as highlighted by Cousino and Hazen's (2013) review, and this should be explored.

SC has been considered a potential mediator in MBIs previously (Van Dam et al. 2011), although only one of the studies in this review included a SC measure (Hou et al. 2014). Previous research with other participant populations has found that SC is a predictor of wellbeing (see Neff 2011). Therefore, SC has the potential to be an important construct when considering the maintenance of wellbeing, and future research may wish to further investigate the role of SC in MBIs and research exploring carer wellbeing.

Further recommendations for future research include that studies investigating the effectiveness of MBIs should, at least, include a mindfulness measure. A number of potentially relevant studies were excluded at the final eligibility stage of the search, as no mindfulness measure was included (e.g. Minor et al. 2006). Whilst there is increasing attention paid in the literature to mindfulness and MBIs, the research is still in its infancy. It is only in the last 10 years that mindfulness research has gained a surge of interest, with the inclusion of MBCT in the NICE guidelines as a recommended alternative to antidepressant medication for recurrent depression (NICE 2004; 2009). Whilst it is generally considered that mindfulness is a mediator of change (Kuyken et al. 2010), it is important to explore the main component of the intervention to understand the mechanisms involved, which is true of any intervention research at such an early stage in development.

An important consideration from this review is the conceptualisation of mindfulness as a construct. Mindfulness within this context may be considered a state-level construct (Baer et al. 2006); however, recently there is increasing recognition that mindfulness may be considered a trait-level construct (Bullis et al. 2014), that is dispositional individual differences that may act as protective factors for wellbeing. Future research should consider the emerging theme of trait mindfulness to help further understand the construct of interest, and for whom MBIs may hold the most benefit.

Conclusions

This review supports existing evidence that MBIs could be useful when considering wellbeing and reduced levels of distress in people (see review by Keng, Smoski, & Robins 2011). In this case, MBIs may be useful for carers of people with a LTC. The review also supports the current understanding that mindfulness potentially plays an important role in protecting the wellbeing of carers. However, as neither mindfulness nor SC were used as primary outcome measures, and the measures of mindfulness varied greatly, there is little conclusive evidence of the relative importance of these constructs in relation to wellbeing.

Given the demonstrated benefits of MBIs and the rapid increase in efficacy studies (Baer 2003), it is important that the field avoids the continued proliferation of programmes without first understanding the processes behind it (Baer et al. 2008;

Harnett & Dawe 2012), as there are increasing risks to the quality, interpretation, treatment fidelity, and dissemination of research findings (Crane, Kuyken, Hastings, Rothwell, & Williams 2010). Despite the exponential rise in MBIs, and now compassion-focussed interventions, they are still in their infancy; and whilst mindfulness appears to be an active ingredient in these interventions, it is unlikely to be the only variable responsible for change. Therefore, it is important for us to explore the constructs involved, and the mechanisms of change for these interventions in the first instance.

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Chapter 2: Empirical Paper

Parental wellbeing when caring for a young person with Type 1 Diabetes: The role of self-compassion and trait mindfulness[2]

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[2] Article prepared for submission to *'Journal of Family Psychology'* for peer review. Please see Appendix E for a copy of journal guidelines for authors.

Abstract

Caring for a person with a long-term condition (LTC) can be difficult. The management of type 1 diabetes (T1D), one of the most prevalent LTCs in children and young people (CYP) can impact on the whole family. Parents are often highly involved in the management of T1D in CYP, and research has found that this can lead to an increase in reported stress levels. Two psychological concepts, self-compassion (SC) and mindfulness have been linked to subjective wellbeing. The current study sought to explore whether trait mindfulness and SC were predictors of wellbeing and perceived quality of life (QoL) in parents (*N* = 152) of CYP with T1D using a cross-sectional web-based questionnaire design. Correlation and regression analyses were performed. Results indicated that mindfulness was not associated with either wellbeing or QoL, however SC was positively correlated with wellbeing and QoL, and was somewhat predictive of parental subjective wellbeing. The findings of the current study suggest that higher levels of SC could be important in the wellbeing of parents of CYP with T1D; and that mindfulness, and how it is measured and conceptualised, may need to be explored further.

Keywords: mindfulness, self-compassion, wellbeing, parents, type-1 diabetes

Introduction

Type 1 Diabetes (T1D) is a condition whereby the pancreas does not produce sufficient insulin to regulate blood glucose. It is one of the most common long-term conditions (LTCs) in children and young people (CYP) in the UK, with a prevalence rate of 33,500 in under 19s (Diabetes UK, 2013). T1D involves complex treatment and management, which is important in order to prevent, or delay, serious long-term complications, including amputation and blindness (Diabetes UK, 2013). For CYP with T1D, parental support is usually expected (Delamater, 2009). Parents therefore play a crucial part in maintaining the physical wellbeing of their child (DeCoster, 2001).

In managing T1D, this caring role demands a change in family routine, but with the parent still trying to maintain some normality for their child (Sherifali & Ciliska, 2006). These increased demands and challenges for the parent can result in family conflict, financial difficulties, social isolation, and fear about the complications of diabetes, leading to increased stress and subsequent burnout (Ray, 2002; Streisand, Swift, Wickmark, Chen, & Holmes, 2005; Walsh, 2002). There is some evidence in the literature that suggests that this continual source of stress, and especially in families where there is increased diabetes-related conflict, can lead to poorer glycaemic control (Whittemore, Jaser, Chao, Jang, & Grey, 2012). The ability for the family to cope is therefore probably important in the successful management of T1D.

When a CYP is diagnosed with T1D the individual and their family go through a process of adjustment. There are many theories of adjustment, with Lazarus and Folkman’s (1984) theory of psychological stress and coping considered as one of the most influential, from which many more specific theories have been postulated. Lazarus and Folkman's (1984) cognitive model of stress and coping considers that when an event happens (i.e. the stressor) then the individual will first appraise the situation before implementing their coping response (problem-focused or emotion-focused). When considering parents of CYP with LTCs, Thompson and Gustafson (1996) developed a transactional stress and coping model specifically focussing on maternal adaptation. They considered that in this context the LTC was seen as the stressor, to which the individual and family system must try to adapt; therefore seeing the LTC as something that impacts on the whole family, with the response/adjustment determined by individual and family coping styles (Thompson & Gustafson, 1996).

Evidence suggests that parents of CYP with T1D may experience the diagnosis as a traumatic experience, with some parents meeting the criteria for posttraumatic stress disorder (PTSD; Landolt, Vollrath, Laimbacher, Ghehm, & Sennhauser, 2005). Parents expect their child to be healthy, therefore when diagnosed with a LTC this can lead to psychological distress or difficulties, particularly symptoms of grief (grieving for the loss of their child's health; Lowes, Gregory, & Lyne, 2004; Seppanen, Kyngas, & Nikkonen, 1999). Parents may worry that actions they did in their past may have contributed to their child's diagnosis (i.e. unjustified guilt), and can be initially overwhelmed by the burden of care (DeCoster, 2001).

A recent systematic review by Cousino and Hazen (2013) reported that levels of parenting stress in caregivers of CYP with LTCs had been extensively researched. Their findings suggested that parents of CYP with LTCs reported significantly higher levels of stress than parents of healthy CYP, but found parenting stress seemed to be unrelated to LTC duration and severity across various LTC populations, including T1D (Cousino & Hazen, 2013). Hullmann and colleagues (2010) found that parents of children with diabetes reported greater general parenting stress than parents of children with cancer or cystic fibrosis. A similar, longitudinal, study by Helgeson and colleagues (2012) compared the distress experienced between parents of children diagnosed with cancer and those of children diagnosed with T1D. They found that although initial distress was higher in parents of a child diagnosed with cancer, their distress lessened with time. Parents of a child diagnosed with diabetes, on the other hand, experienced distress over a longer period of time, which may be due to the fact that a cure is not currently available for people with T1D (Helgeson, Becker, Escobar, & Siminerio, 2012).

There is, however, variability in coping amongst parents of CYP with T1D and some show greater adjustment to the diagnosis (Tugade & Fredrickson, 2004; Whittemore et al., 2012). Whilst some studies have explored adaptation to chronic conditions, finding that socio-ecological factors (such as family support), intrapersonal factors, and coping strategies played important roles (Brown, Fouche, & Coetzee, 2010); the Cousino and Hazen (2013) review concluded there was limited research exploring why some parents cope better, and what contributes to parent’s psychological wellbeing when caring for a child with a LTC. They suggested that future research should investigate ways to promote positive health within parents; and that interventions could focus on preventing or reducing stress, and promoting parental coping (Cousino & Hazen, 2013; Hoff et al., 2005). It has been argued that a focus on the positive can promote resilience in non-clinical populations (i.e. parents of children with LTCs; see Wood & Tarrier, 2010).

Two emerging areas of research within a positive psychology framework are trait mindfulness and self-compassion (SC). Whilst SC and mindfulness are closely related constructs, they are not the same (MacBeth & Gumley, 2012). Mindfulness can be defined as paying attention in a particular way, while being present-focussed and non-judgmental (Kabat-Zinn, 1990). This is in comparison to rumination and worry, which are common occurrences for many people (Splevin, 2012). Mindfulness emphasises awareness to all experiences and senses (Van Dam, Sheppard, Forsyth & Earleywine, 2011). There are currently two ways to consider mindfulness; trait and state (Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006). State mindfulness is a competence that can be acquired, such as through mindfulness-based interventions (MBIs), whereas trait mindfulness relates more to personality or a natural ability to be mindful (Baer et al., 2006; Brown & Ryan, 2003).

It is argued that whilst state and trait mindfulness are related, they are different constructs (Woodruff et al., 2013). There has been a proliferation of research evaluating MBIs, which has repeatedly demonstrated that MBIs have a positive effect on subjective wellbeing and mood (Baer, 2003; Nyklicek & Kuijpers, 2008; Shapiro, Brown, Thoresen, & Plante, 2011), but the literature about trait mindfulness is still in its infancy (Bullis, Bøe, Asnaani, & Hofmann, 2014). Trait mindfulness is considered to have five facets (observing, describing, acting with awareness, non-judging of inner experience, and non-reactivity to inner experience), validated by multiple studies (Baer, Smith, & Allen, 2004; Baer et al., 2006; Christopher et al., 2012; Keng, Smoski, & Robins, 2011).

Trait mindfulness is associated with multiple aspects of psychological health (Keng et al., 2011). In terms of positive mental health outcomes, trait mindfulness is associated with increased life satisfaction, self-esteem and optimism (Brown & Ryan, 2003). Individuals with higher trait mindfulness have also been found to pay attention to negative emotional experiences in less judgmental and more accepting ways (Kimberly, Hartmann, & Fredickson, 2010), as well as persevering with difficult tasks for longer without reacting or giving up (Evans, Baer, & Segerstrom, 2009). Trait mindfulness has also demonstrated negative correlations with symptoms of depression, anxiety and stress-related symptoms (Cash & Whittingham, 2010).

SC, on the other hand, relates to self-kindness in the face of personal crises (Neff, 2003a). Neff (2003a) described three components to SC; self-kindness and understanding to oneself versus self-judgment, seeing experiences as a whole human experience ('common humanity') rather than in isolation, and holding painful thoughts and feelings in awareness ('mindfulness') rather than become over-involved with them. SC additionally emphasises the emotional components such as feelings of care and understanding (Woodruff et al., 2013). Self-compassionate individuals report greater empathetic concern, altruism, perspective taking, and forgiveness (Neff & Pommier, 2013).

Studies exploring SC have shown that higher SC is associated with less negative feelings (Neff, 2003a; Raes, 2010; Van Dam et al., 2011); and greater positive mental health (Hollis-Walker & Colosimo, 2011; Neff, Rude, & Kirkpatrick, 2007), such as experiencing happiness, optimism, wisdom, curiosity and emotional intelligence (Heffernan, Griffin, McNulty, & Fitzpatrick, 2010; Hollis-Walker & Colosimo, 2011; Neff et al., 2007). Another strength of being self-compassionate is the ability to cope effectively with life stressors (Costa & Pinto-Gouveia, 2011; Vettese, Dyer, Li, & Wekerle, 2011).

A number of studies have explored these concepts separately (Woodruff et al., 2013); however, only five studies to date, to the authors' knowledge, have been conducted comparing these concepts together as traits. When considering psychological wellbeing, Van Dam and colleagues (2011) reported that SC was a stronger predictor of psychological wellbeing and perceived quality of life (QoL) than a single-factor mindfulness measure. Hoge and colleagues (2013) reported that increased mindfulness (when measured by a multi-faceted mindfulness measure) was a stronger predictor than SC in relation to protecting people against feeling disabled by generalized anxiety. In contrast, Woodruff and colleagues' (2013) utilized a multifaceted measure of mindfulness to compare with SC. They found that SC was a better predictor of psychological wellbeing when total scores were used; but when subscales were regressed, both had unique predictive utility. Hollis-Walker and Colosimo (2011) also used a multi-faceted measure of mindfulness, finding that both mindfulness and SC were equally important predictors whilst still being unique and different constructs. Similarly, Baer and colleagues' (2012) analysed sub scales on both a SC scale and multi-faceted mindfulness questionnaire, finding that a combination of both these factors played an important role in improved wellbeing. However, to date, this work has largely focused on these relationships within the general population.

Given that increased parental stress is associated with poorer outcomes in CYP with T1D, it seems clinically relevant to extend the work of factors that may protect wellbeing and therefore reduce parental stress to parents of CYP with T1D. A better understanding of the constructs of trait mindfulness and SC in this group may also contribute to, and inform, clinical interventions for those who support CYP with T1D.

Aims and Hypotheses

The aims of the study were to consider the concepts of SC and mindfulness as trait constructs in exploring what contributes toward parent resilience. It is hypothesised that: (1) trait mindfulness and SC would be positively correlated with parental subjective wellbeing and perceived QoL, (2) the positive facets of SC would be positively correlated with parental subjective wellbeing, and (3) higher levels of SC and trait mindfulness would be protective factors against parental stress associated with parenting a child with T1D.

The research also aims to consider which facets of SC are the strongest predictors of subjective wellbeing (Hypothesis 4), and whether SC and trait mindfulness are independent predictors of subjective wellbeing (Hypothesis 5) above and beyond what is contributed by those constructs that are already theoretically linked to wellbeing (i.e. perceived QoL and perceived parental stress). Finally, the study aimed to explore any other notable features of this group, specifically, whether the age of the child and the time since the child was diagnosed plays a role in parental subjective wellbeing.

Method

Participants

Participants were 152 parents of CYP with T1D from the UK. Participants were included in the study if they were 1) 18-years-old or older, 2) had a CYP under the age of 18 with a diagnosis of T1D, 3) a resident of the UK, and 4) could understand written English. Parents ages ranged from 26-55 years (*M* = 40.27, *SD* = 6.24), with an average CYP age of 9.84 years (range = 2-17, *SD* = 3.57). The average time since T1D diagnosis was 4.15 years (*SD* = 3.13), ranging from 0-14 years. The majority of the participants were female (94.7%), married/cohabiting (87.5%), and did not have prior meditation practice (90.1%; see Table 1 for full demographic data).

Power and precision

Cohen (1988) recommends that in the behavioural sciences researchers should aim to recruit numbers sufficient to detect minimum medium effects at .80 power at an alpha of .05. Based on G-Power (Faul, Erdfelder, Lang, & Buchner, 2007) calculations, 82 participants are required for a correlation analysis (two-tailed; r = .3), and 135 participants are required for hierarchical multiple regression ($f^2 = 0.15$), based on fourteen predictors. In order to incorporate both analyses, total N =135 was required to achieve .80 power at an alpha of .05. The minimum estimated sample size for the study was exceeded (actual N = 152) and achieved power was .86.

Table 1
Participant demographic information

Demographics	*N*	%
Gender		
Male	8	5.3
Female	144	94.7
Employment Status		
Full time	39	25.7
Part time	50	32.9
Self-employed	10	6.6
Unemployed	0	0
Student	5	3.3
Retired	0	0
Homemaker	48	31.6
Marital Status		
Married/cohabiting	133	87.5
Single	6	3.9
Divorced/separated	12	7.9
Widowed	1	0.7
Previous or current meditation practice		
Yes	15	9.9
No	137	90.1

Measures (see Appendix F)

Demographic questionnaire. Participant demographic information was collected, including gender, age, marital status, employment status, age of CYP, time since CYP was diagnosed, and current mindfulness/meditation practice.

Warwick Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007). The WEMWBS is a 14-item scale of wellbeing, looking at subjective wellbeing and psychological functioning (Tennant et al., 2007). The measure is positively worded, based on the previous two weeks, and participants mark their response on a 5-point Likert Scale ranging from ‘not at all’ to ‘all of the time’. It has been validated in the UK on those aged 16 and above (Tennant et al., 2007). Previous research with a large non-clinical sample has found an average score of 50.7 (Braunholtz, Davidson, Myant, & O’Connor, 2007). The WEMWBS has good internal consistency, with a Cronbach alpha coefficient reported of .89 reported (Tennant et al., 2007). In the current study internal consistency was high with $\alpha = .95$.

World Health Organization Quality of Life-BREF (WHOQOL-BREF; WHOQOL Group, 1998). The WHOQOL-BREF is a 26-item measure assessing QoL (WHOQOL Group, 1998) across four domains: psychological, physical, social functioning, and environment, plus two questions relating to general QoL. Participants report the frequency of a range of experiences and the extent to which they have been satisfied with a variety of areas over the past month on a 5-point Likert scale. An overall score can be calculated, with higher scores indicating higher perceived QoL. It has been used worldwide, and validated in field studies in a number of countries (Skevington, Lofty, & O’Connell, 2004). It has good to excellent internal consistency when used as an overall measure of QoL ($\alpha = .81$; Pomeroy, Tennant, & Young, 2013), demonstrated in a number of different participant groups (clinical and non-clinical samples; Skevington et al., 2004). In the current study *α* = .85.

Pediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, & Kazak, 2001). The PIP is a 42-item self-report measure for carers of children with a chronic health condition, which measures parent/carer stress (Streisand et al., 2001). It includes questions covering communication, emotional functioning, medical care, and role functioning. Ratings are on a 5-point Likert scale for both difficulty and frequency. Higher scores on the PIP correspond to higher levels of parenting stress, with scores ranging greatly in previous studies. Only the total scores of the PIP difficulty (PIP-D) scale were used in the statistical analysis. Streisand and colleagues' (2001) study of parents of children with cancer found an average score on the PIP-D scale of 112.4. The PIP-D scale has good internal consistency (*α* = .96; Streisand et al., 2001), which was replicated in the current study; and has been validated for use with parents of children with T1D (Lewin et al., 2005).

The Self-Compassion Scale (SCS; Neff, 2003b). The SCS is a 26-item questionnaire that measures attitudes toward the self (Neff, 2003b). It is scored on a 5-point Likert scale ranging from one (almost never) to five (almost always). Items are positively and negatively worded and can be divided into six subscales (three positive: self-kindness, common humanity, and mindfulness; three negative: self-judgment, isolation, and over-identification). The SCS also yields a total SC score in addition to the subscale scores. The SCS has demonstrated good reliability in non-clinical samples, with internal reliability high (*α* > .9) and the six separate subscales demonstrating good internal consistency (*α* > .7; Neff, 2003b). In the current study, overall scale *α* = .93, and subscales ranged from *α* = .77 - .84.

Five Facet Mindfulness Questionnaire – Short Form (FFMQ-SF; Bohlmeijer, ten Klooster, Fledderus, Veehof, & Baer, 2011). The FFMQ-SF was used as a measure of trait mindfulness. It is a 24-item measure comprising of five factors (observing, describing, acting with awareness, non-judging of inner experience, and non-reactivity to inner experience) that are linked to elements of mindfulness (Bohlmeijer et al., 2011). It is scored on a five-point Likert scale ranging from one (never or very rarely true) to five (very often or always true). The FFMQ-SF was designed to measure trait mindfulness, as opposed to state, mindfulness (Bergomi, Tscacher, & Kupper, 2013), with a higher total score indicative of greater trait mindfulness. The FFMQ-SF total score has reported good internal consistency (α = .79; Batzel, 2013). In the current study the internal consistency was adequate (α = .66).

Design

A cross-sectional design was used, via a web-based survey.

Procedure

After the study received ethical approval from the University of Liverpool Ethics Committee (see Appendix G), the study was advertised via Diabetes UK, and a specially set up research Twitter account which allowed tweets by the researcher and retweets by the online community, in order to gather responses from a range of individuals. Participants were recruited from 31st January 2014 until 25th April 2014.

The procedure was typical of internet-based research (BPS, 2013), with participants accessing the advertisement for the study where a study link would redirect them to an information page (see Appendix H). If participants wished to take part they could click to take them through to an informed consent page (see

Appendix I). Following completion of consent, participants then commenced the questionnaires, with each participant completing the same set of questionnaires, online, in a place of their choosing. No identifiable information was collected relating to participant responses. The questionnaires took approximately 20 minutes to complete, and once completed, a link redirected participants to a debriefing page. Participants were also invited to enter a prize draw upon completion of the study, although participation was voluntary.

Statistical analytic procedure

Preliminary analyses were conducted in order to screen the data and ensure that the assumptions of normality, linearity and homoscedasticity were not violated prior to conducting any further analyses. The assumptions were violated for a number of the variables, and therefore parametric analysis could not be conducted (see Appendix J). Therefore, Spearman's correlation coefficients were conducted to explore hypotheses one, two and three, as well as exploring any other notable features of this group. Regression residuals were also checked for normality and homoscedasticity, and as these assumptions were not met, hierarchical multiple regression analysis was used to explore hypotheses four and five, with significant correlates entered in the regression model. This utilised the technique of bootstrapping. Bootstrapping estimates the properties of the distribution from the sample data (Field, 2013). Bias corrected accelerated confidence intervals (BCa) were selected, as they are deemed more accurate than a 95% percentile confidence interval (Efron & Tibishirani, 1993, cited in Field, 2013). Collinearity diagnostics were run to check for Multicollinearity (Pallant, 2013), which was found to not be an issue in the current data set (see Appendix K).

Following initial data screening to check the underlying assumptions, one extreme outlier was found when analysing the data for the FFMQ-SF. When the raw data was consulted it was a true outlier (greater than 3 standard deviations from the mean for FFMQ-SF). However, when all responses for this case were reviewed, it indicated that their results were not outliers on all scales. Field (2013) and Pallant (2013) suggest reviewing the 5% Trimmed Mean and comparing it with the mean values. If they are very different from each other then consideration should be given to remove the outlier or adjust its score. On reviewing the means and 5% Trimmed Means, all values were relatively similar (see Table 2). Initial analyses were also conducted with and without this case, and found very little difference between the outcomes. A decision was taken to keep the case in all analyses.

Results

Figure 1 details the flow of participants who accessed the study and completed the questionnaires. Any participants with incomplete or missing data were removed from final analysis. It was noted that most of those who did not complete the study dropped out after completing only the demographics or first measure (30% of the 304 who had consented dropped out by the end of the first measure).

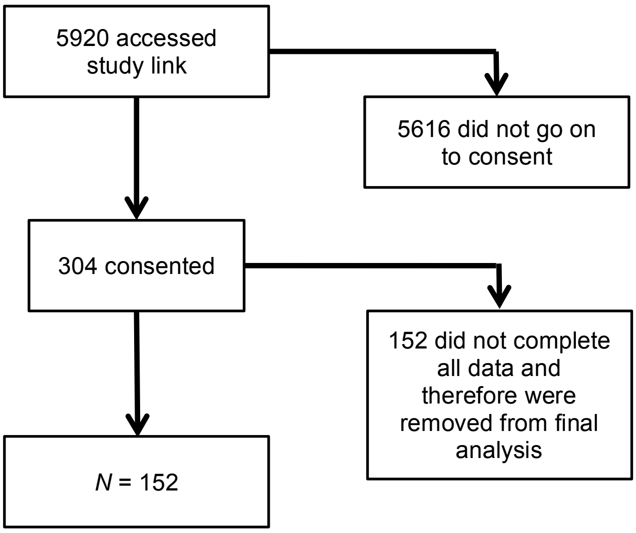

Figure 1. Response rate throughout data collection

Means and standard deviations were computed and are reported in Table 2.

Table 2

*Descriptive statistics for study measures (*N *=152)*

Measure	*M (SD)*	95% CI	5% Trimmed Mean	Range	
				Potential	Actual
WEMWBS	43.9 (10.4)	[42.3, 45.6]	43.8	14-70	14-70
WHOQOL-BREF	81.5 (12.1)	[79.6, 83.5]	81.7	26-130	48-109
PIP-D	115.3 (33.9)	[109.9, 120.8]	115.2	42-210	47-210
FFMQ-SF total	70.3 (8.8)	[68.9, 71.7]	70.7	24-120	24-93
SCS total	65.7 (17.6)	[62.9, 68.5]	65.4	26-130	28-115
SCS mindfulness	11.2 (3.2)	[10.6, 11.7]	11.1	4-20	4-20
SCS common humanity	10.9 (3.6)	[10.4, 11.5]	10.9	4-20	4-19
SCS self-kindness	11.5 (4.1)	[10.9, 12.2]	11.4	5-25	5-23
SCS isolation	13.3 (4.0)	[12.7, 13.9]	13.4	4-20	4-20
SCS self-judgment	13.4 (3.9)	[12.8, 14.1]	13.6	5-25	4-20
SCS over identification	13.2 (3.9)	[12.6, 13.9]	13.3	4-20	5-20

Note. WEMWBS = Warwick Edinburgh Mental Wellbeing scale; WHOQOL-BREF = World Health Organization Quality of Life Scale-BREF; PIP-D = Pediatric Inventory for Parents-Difficulty scale; FFMQ-SF = Five Facet Mindfulness Questionnaire-Short Form; SCS = Self-compassion Scale; CI = confidence interval.

Trait mindfulness and self-compassion with parental subjective wellbeing and perceived QoL

The relation between parental wellbeing (measured by the WEMWBS), perceived QoL (measured by the WHOQOL-BREF), trait mindfulness (measured by the total score of the FFMQ-SF) and SC (measured by the total score of the SCS) were investigated using the non-parametric test of Spearman's correlation coefficient (see Table 3). As predicted, higher levels of wellbeing was associated with higher reported SC, with a large, positive correlation between parental subjective wellbeing and SC ($r_s = .525$, $n = 152$, $p < .001$). Perceived QoL and total SC scores indicated a moderate positive relationship ($r_s = .481$, $n = 152$, $p < .001$), with higher perceived QoL associated with higher reported SC. However, non-significant, small, negative relationships between trait mindfulness and parental subjective wellbeing and perceived QoL were observed ($r_s = -.126$, $n = 151$, $p = .122$, and $r_s = -.108$, $n = 152$, $p = .183$). Therefore results indicate only partial support for Hypothesis 1, as only SC was found to be significantly positively associated with parental subjective wellbeing and perceived QoL.

Positive facets of self-compassion with parental subjective wellbeing

The relationship between parental subjective wellbeing and the positive facets of SC (the mindfulness, common humanity and self-kindness subscales of the SCS) are reported in Table 3. All three positive facets of SC were positively, moderately associated with parental subjective wellbeing (mindfulness facet, $r_s = .360$, $n = 152$, $p < .001$; common humanity facet, $\mathrm{r_s} = .300$, $\mathrm{n} = 152$, $p < .001$; and self-kindness facet, $r_s = .332$, $n = 151$, $p < .001$, respectively), and therefore lending support to

Hypothesis 2 that higher reported levels of the positive facets of SC were associated with higher reported parental subjective wellbeing.

Higher levels of self-compassion and trait mindfulness as protective factors against parental stress associated with parenting a child with T1D

The relationship between SC, trait mindfulness and perceived parental stress (measured by the PIP's difficulty scale) was investigated using the non-parametric test of Spearman's correlation coefficient (see Table 3). Significant, yet small, negative correlation was observed between SC and perceived parental stress (r_s = -.295, n = 152, $p < .001$). Higher levels of perceived parental stress was moderately, positively associated with higher levels of reported trait mindfulness (r_s = .346, n = 152, $p < .001$). Given trait mindfulness demonstrated a positive relationship with parental stress, Hypothesis 3 could only partially be accepted, with results suggesting support for a negative relationship between SC and parental stress only.

Other notable features of this group: age of the child and the time since the child was diagnosed with parental subjective wellbeing?

The age of the child and the time since the child was diagnosed, along with parental subjective wellbeing were also explored (see Table 3). There was a small, positive, correlation between the time since child was diagnosed and parental subjective wellbeing (r_s = .160, n = 152, p = .049), suggesting the longer the length of time since diagnosis could be associated with increased parental subjective wellbeing. No association was found between age of child and parental subjective wellbeing.

Similarly, when investigating reported parenting stress (measured by the PIP-D) and time since diagnosis, there was a small, negative correlation (r_s = -.167, n =

152, *p* = .04). This suggests an association between the length of time the child has been diagnosed and the amount of parent-reported stress (i.e. longer time since diagnosis associated with less reported parental stress). Again, no association was found between age of child and reported stress.

Table 3

Correlations of studied variables

	WEMWBS	WHOQOL-B	PIP-D	FFMQ-SF-T	SCS-T	SCS-MF	SCS-CH	SCS-SK	SCS-I	SCS-SJ	SCS-OI	Age	CYP Age	T since D
WHOQOL-B	.785**													
PIP-D	-.561**	-.556**												
FFMQ-SF	-.126	-.108	.346**											
SCS-T	.525**	.481**	-.295**	.132										
SCS-MF	.360**	.337**	-.142	.349**	.786**									
SCS-CH	.300**	.288**	-.089	.243**	.688**	.696**								
SCS-SK	.332**	.287**	-.086	.229**	.768**	.680**	.596**							
SCS-I	-.556**	-.482**	.413**	.118	-.771**	-.423**	-.331**	-.403**						
SCS-SJ	-.449**	-.374**	.327**	.015	-.798**	-.443**	-.328**	-.547**	.699**					
SCS-OI	-.468**	-.453**	.317**	.001	-.805**	-.534**	-.386**	-.430**	.696**	.651**				
Age	-.012	-.005	-.128	-.104	-.073	-.125	-.134	-.011	.025	.009	.041			
CYP Age	-.095	.028	-.052	-.008	-.094	-.101	-.006	-.039	.140	.076	.117	.453**		
T since D	.160*	.088	-.167*	-.140	.078	.013	.079	.061	-.044	-.064	-.083	.277**	.424**	
Meditation	-.062	-.133	.022	.096	.081	.099	.199*	.130	.013	-.033	-.043	-.034	-.055	.040

Note. WEMWBS = Warwick Edinburgh Mental Wellbeing Scale; WHOQOL-B = World Health Organisation Quality of Life-BREF; PIP-D = Pediatric Inventory for Parents-Difficulty scale score; FFMQ-SF = Five Facet Mindfulness Questionnaire-Short Form (total score); SCS-T = Self-Compassion Scale-total score; SCS-MF = Self-Compassion Scale-Mindfulness scale; SCS-CH = Self-Compassion Scale-Common Humanity scale; SCS-SK = Self-Compassion Scale-Self-Kindness scale; SCS-I = Self-Compassion Scale-Isolation scale; SCS-SJ = Self-Compassion Scale-Self-judgment scale; SCS-OI = Self-Compassion Scale-Over Identification; CYP = child or young person; T = time; D = diagnosis.

*p<0.05, **p<0.01

Which facets of self-compassion are the strongest predictors of subjective wellbeing? Are self-compassion and trait mindfulness differently associated to subjective wellbeing (i.e. are they independent predictors)?

Hierarchical multiple regression was used to assess whether trait mindfulness and SC predict perceived wellbeing, after controlling for other influential variables that were significantly correlated, or theoretically linked, to wellbeing (in this case only CYP time since diagnosis, the WHOQOL-BREF and PIP-D were included; see Table 4). As only significant correlates were entered into the regression model, trait mindfulness was not included in the analysis. CYP time since diagnosis, the WHOQOL-BREF and PIP-D were entered into the model at Step 1, explaining 67.2% of the variance in parental subjective wellbeing (R^2 = .672, F [3, 148] = 101.01, p <.001). Including the SCS total at Step 2 resulted in the total variance explained by the model = 70%, F (4, 147) = 85.6, p < .001. This indicates that SC explained an additional 2.8% of the variance in wellbeing, after controlling for CYP time since diagnosis, QoL and perceived parenting stress, R^2 = .028, F change (1, 147) = 13.59, p < .001. In the final model, only three of the variables were statistically significant with the wellbeing scale (WHOQoL-BREF β = .603, PIP-D β = -.188, SCS β = .189).

When the positive facets of the SCS were added into the model they did not provide any further significant variance (0.1%, p = .91). When all facets were entered they did not provide any further significant variance (0.4%, p = .86), therefore suggesting that the total SCS was a greater predictor of wellbeing than the individual facets.

Table 4

Hierarchical multiple regression analyses predicting subjective parental wellbeing

Predictor	*b*	SE *B*	*β*	*p*
Step 1				
CYP time since D	.146 (-.162, .461)	.157	.044	.347
WHOQOL-BREF	.587 (.496, .683)	.047	.687	.001
PIP-D	-.060 (-.097, -.019)	.018	-.195	.003
Step 2				
CYP time since D	.147 (-.136, .430)	.151	.045	.331
WHOQOL-BREF	.515 (.410, .611)	.052	.603	.001
PIP-D	-.058 (-.095, -.017)	.017	-.188	.001
SCS	.111 (.052, .173)	.029	.189	.001

Note. R^2 = .672 for Step 1; R^2 = .700 for Step 2; ΔR^2 = .028 for Step 2 (p < .001). CYP = child or young person; D = diagnosis; WHOQOL-BREF = World Health Organization quality of life-BREF scale; PIP-D = Pediatric Inventory for Parents-Difficulty scale; SCS = Self-compassion scale.

Discussion

The aim of the study was to explore the role of trait mindfulness and SC in parental wellbeing when caring for a CYP with T1D, following recent studies in different populations by Baer and colleagues (2012), Hoge and colleagues (2013), Hollis-Walker and Colosimo (2011), Woodruff and colleagues (2013) and Van Dam and colleagues (2011). This is the first study, to the author's knowledge, in which trait mindfulness and SC have been explored in a group of parents of CYP with T1D.

The main finding was that trait mindfulness did not appear to be associated with subjective parental wellbeing. Consistent with previous research (e.g. Van Dam et al., 2011; Woodruff et al., 2013), SC was found to be positively related to subjective parental wellbeing and perceived QoL, in that increased SC was associated with increased perceived wellbeing and QoL; but SC's predictive value in relation to subjective wellbeing was small. This adds to the growing research that considers that SC may be an important construct in wellbeing (Brown & Ryan, 2003; Neff, 2003a; Woodruff et al., 2013). Higher SC was also found to be associated with lower parental-reported stress, the converse was found with trait mindfulness, with higher mindfulness scores related to higher parental-reported stress. The majority of the SC reported findings were moderate-to-large in size, indicating relatively strong associations between SC, parental subjective wellbeing, perceived QoL and parental-reported stress. However, the level of variance for SC was extremely small, with QoL showing the greatest predictive value when entered into a model predicting parental subjective wellbeing. The study also found that the longer a CYP had been diagnosed with T1D the greater the reported parental wellbeing, suggesting that parents may adjust to the diagnosis of T1D over time.

The mean scores on all measures were notably different to mean scores from many previous studies using these measures. For example, in this study the WEMWBS (Tennant et al., 2007) had an average score of 43.9, in comparison to Braunholtz and colleague’s (2007) study where the average in the general Scottish population was 50.7. The scores observed here, however, do appear to be in line with a previous parent study of parents undergoing parenting programmes for children with behavioural problems, whose average pre-treatment scores ranged between 42.4-45.3 (Lindsay, Strand, & Davis, 2011). This suggests that parents of CYP with T1D report lower subjective wellbeing than the general population, but potentially this is in line with other parents managing difficult experiences with their children. The scores are also relatively close to the cut off of 43.5 that has recently been suggested to indicate greater risk of clinical depression (Bianco, 2012).

Whilst the study found that lower parental-reported stress was associated with higher SC, this does not mean that parents do not find caring for a CYP with T1D stressful. Instead, it may suggest that SC allows awareness of the challenges they face without feeling overwhelmed and by showing a level of kindness towards their experience of stress (Leary, Tate, Adams, Allen, & Hancock, 2007). Perhaps greater

SC, and a kinder focus on one's own thoughts, feelings and experiences, better predicts and promotes wellbeing than awareness of the present moment and the 'letting go' with intention (i.e. mindfulness). This lends itself to the findings of Woodruff and colleague's (2013) who reported that SC was a greater predictor of wellbeing in comparison to mindfulness and psychological inflexibility. They suggested that this was, in part, due to SC being more easily defined and understood semantically than mindfulness. This is also in line with Van Dam and colleague's (2011) findings, which found that SC was a better predictor of wellbeing and perceived QoL than mindfulness in a sample of those who were seeking support for anxiety. The findings of the study are, however, in contrast to studies by Baer and colleague's (2012) and Hollis-Walker and Colosimo (2011), who found that both mindfulness and SC were equally important predictors whilst still being unique and different constructs in samples of both meditators and non-meditators.

The current findings report some interesting results, as trait mindfulness did not correlate with wellbeing when analysed, and the relation with parent-reported stress suggests that higher levels of stress was associated with higher levels of mindfulness. Also, there was no significant relationship between the total scores on the scales for SC and mindfulness. This is noteworthy, as other studies have consistently demonstrated a relationship between the two constructs and with mindfulness and psychological health (Baer et al., 2012; Hollis-Walker & Colosimo, 2011; Woodruff et al., 2013; Van Dam et al., 2011). The findings reported here suggest that trait mindfulness, or the natural ability to be mindful, may not be as important a factor as the ability to be compassionate towards the self for parents of CYP with T1D. Whilst there has been limited published use of the FFMQ-SF in non-clinical and non-intervention populations, in a recent study of chronic pain patients

(Braun, 2013) the average FFMQ-SF score at baseline (intervention study) was around 80.4, whereas this study found the average to be 70.3, which suggests the current sample are less mindful. On average, SC scores were lower in this population than in previous studies of the general population (Neff, 2003a). Neff (2003b) suggests that the average SCS score in the general population will be around 78, however in this study the mean score was only 65.7, which could suggest that parents of CYP with T1D find it difficult to extend kindness to themselves when dealing with the diagnosis of T1D in their child. This was also reflected in the low additional variance of SC in the regression model.

The study did not exclude anyone who may have been accessing psychological support, and did not include questions on whether people were suffering with acute mental health problems, however this is something to consider with this population as numerous studies have found increased stress, and risk of PTSD (e.g. DeCoster, 2011; Landolt et al., 2005). It was found that the PIP-D average score in this study (115.3) were marginally higher than those reported by Streisand and colleagues' (2001) study of parents of children with cancer (112.4), this is in line with Helgeson and colleagues (2012) who suggested that parents of CYP with T1D often report greater levels of stress than parents of CYP with cancer due to the incurable nature of T1D.

One consideration with regard to the findings of this study is parent and carer identity. Being a parent can be stressful in itself – supporting a child with T1D can act as an additional stressor, which may impact on role identity as a parent and/or carer. Cousino and Hazen (2013) report that parents of children with LTC experience significantly higher levels of stress than parents of healthy children, which suggests a difference in the two roles of parent and carer; and stress can remain high even after long periods following diagnosis. Whittemore and colleagues (2012) found that parenting roles changed considerably as a result of their child being diagnosed with T1D, and this meant that parents experienced changes to the normal parent-child relationship, having to regain a feeling of competence in parenting, whilst also caring and monitoring their child’s physical wellbeing. The current findings support this, with higher parental subjective wellbeing positively associated with time since diagnosis, suggesting some process of acceptance or adjustment over time may be at play.

Gilbert and Procter (2006) have suggested that SC creates resilience in people by deactivating the threat system, which leads to feelings of stress and anxiety, and activates the caregiving systems, associated with safety and reduced stress. Therefore, it is possible that SC may play a key role in promoting wellbeing in parents, who are also carers. Conversely, mindfulness is negatively associated with rumination and worry (Cash & Whittingham, 2010). Parents who are carers may, however, be less mindful as a consequence of their caring role. For example, their immediate tasks are associated with caring for a child with T1D that requires planning (e.g. meal times, injections, etc.). Moreover, there are long-term complications that are associated with T1D, such as risk of blindness, amputations, and heart disease (Diabetes UK, 2013). Such long-term complications may be legitimate worries, and parents who are carers may worry about the future, and ruminate about the past, more. Rumination is considered to be orthogonal to mindfulness (Williams, Teasdale, Segal, & Kabat-Zinn, 2007).

Limitations of study

There are a number of limitations of the study. First, the results are cross-sectional, and therefore causality cannot be inferred from any of the associations discussed. Second, the study sample consisted of mainly women. Despite the study being advertised online, which had hoped to draw more males, only eight men completed all questionnaires. This is not representative of the general population, but follows the demographic results of previous studies in this area (e.g. Woodruff et al., 2013). Results may differ if there was a more equal gender distribution; however, it may be that with this population, women are the main carers for CYP with T1D, as found in a review by Whittemore and colleagues (2012). Third, there was no screening of symptom severity for participants (i.e. those requiring psychological support could have participated in the study), which may have impacted on the results. Average wellbeing scores were lower than in other studies and there was a wide range in the wellbeing and stress scores, which although is not unusual, could be explained by this limitation.

Fourth, whilst the Internet is a useful tool in order to gather large amounts of data in a short amount of time and limit experimenter effects, it does have a number of disadvantages. This study found that there were a high number of dropouts/incomplete questionnaires (50%) for which the data had to be removed. Whilst no reasons were provided at the time, it could be inferred that a lack of input from the researchers may have led to reduced motivation or commitment to complete the questionnaires. Also, it could be that this participant group, who already have a number of daily demands, could not give their time to the study, and therefore withdrew. When conducting future on-line research, it is possible that a save option could be incorporated so that participants could return to the study at a later date.

Another option, with regards to the high number of incomplete questionnaires, could be to include all the data gathered, including those who had not completed all of the questionnaires. Multiple imputation, whereby any missing values are replaced by plausible values, is one strategy that can be used to deal with missing data. However, this option was not considered given that the study was exploratory and voluntary in nature; therefore, the researchers wanted to gather as much true data as possible.

Fifth, the issue of overlapping constructs should be considered, particularly in relation to the measures utilised. As discussed in the introduction, mindfulness and SC have been considered to be overlapping but distinct concepts (MacBeth & Gumley, 2012); however, in this study they did not show the same relationships with wellbeing as previously demonstrated, which may be linked to the measures of SC and mindfulness used. Also, importantly, the measures used to consider SC and wellbeing could be argued to contain similarly themed items, although the SCS also included negatively worded items. Therefore, we should consider that whilst SC and mindfulness measures in this study allowed us to explore those ideas as two independent constructs, perhaps SC was not independent of wellbeing, and therefore the results may need to be interpreted with caution.

Sixth, we should also consider the overlap between QoL and wellbeing (Hird, 2003), as they too have been deemed similar constructs. Although many argue that it is important to keep the definitions of wellbeing and QoL separate (Camfield & Skevington, 2008); therefore, it is worth bearing in mind in this study that wellbeing was seen as a focus on positive assets, with QoL considering difficulties (including physical health and social areas) too. Research suggests that if someone reports that their physical health is not good (e.g. lack of sleep) then their subjective wellbeing may well be impacted (i.e. reduced; Debono & Cachia, 2007), therefore it could be seen that QoL could be a predictor of wellbeing. Likewise, with parental reported stress, it is known that high stress levels can impact on wellbeing (particularly seen with work related stress, which could be considered similar to the parental role of caring for a CYP with T1D; Shapiro, Brown, & Biegel, 2007). Therefore, in the hierarchical regression both variables were considered important to place in the model first, and therefore control them when SC was added. Therefore, controlling for these variables allowed the researcher to see what contribution SC had to wellbeing, above and beyond that of QoL and parental stress. Controlling these then made the actual results more useful in terms of the research questions posed.

Finally, despite the FFMQ-SF not being statistically associated with parental wellbeing, the mindfulness subscale of the SCS was related to parental wellbeing. This is a finding not in line with the current existing literature. On reflection, the study reported only adequate internal consistency of FFMQ-SF ($\alpha = .66$), indicating that perhaps it was not a valid measure for the population in hand as this was not comparable to research with other populations. This could suggest that the measure was not measuring what it intended. Currently there are over seven different measures of mindfulness, which made selecting an appropriate measure for this study difficult, although best efforts were made to select an appropriate trait measure of mindfulness that was based on a factor analytic study of five independent mindfulness measures (Baer et al., 2006). Researchers continue to debate over whether to use a single facet definition (Brown & Ryan, 2003) or more than two (Herbert & Cardacciotto, 2005, cited in Woodruff et al., 2013). Woodruff and colleagues (2013) also considered that using a multifaceted measure might not be as useful as a single faceted measure in non-clinical populations due to the wider variation in mindfulness scores in comparison to clinical populations. However, Baer and colleagues (2006) argue that using a total score only could weaken the relationship between variables. SC could possibly fall victim to similar complications as measures of mindfulness due to its multi-faceted nature, however a number of studies have suggested that SC is more easily definable and attitudes towards the self may be easier to access (Van Dam et al., 2011; Woodruff et al., 2013). It is therefore possible that the results of this study could reflect more about the measures rather than the constructs under investigation.

Future research recommendations

Despite the limitations of this study, the results support the hypothesis that SC could be an important construct in parental subjective wellbeing, although this relationship is relatively small after including other variables. The results lend support to the growing research that emphasises the importance of enhancing SC. Recent research suggests that SC can be improved through training to reduce stress and improve psychological wellbeing (Gilbert & Procter, 2006; Neff & Germer, 2013).

There is still caution raised regarding compassion-based practices when people are vulnerable, but in the general population and caring roles it may be important to consider whether SC training should become more available. Moreover, this study found no evidence to support that mindfulness was important in this population, however, as mindfulness scores were relatively low, perhaps mindfulness training could still be useful in this population given the numerous benefits it is reported to have, including increased SC (Kuyken et al., 2010).

Parents and CYP dealing with T1D often struggle to manage the condition when there are high levels of family stress, and this can result in poor blood glucose levels leading to longer term complications in CYP. In an effort to promote positive health in CYP with T1D and their parents, it is possible that parenting stress could serve as a modifiable intervention target. By aiming to prevent or reduce parent stress this could lead to indirect positive effects for CYP. Continued examination of protective factors and coping strategies will better inform future interventions (Wood & Tarrier, 2010).

Finally, given the surge of interest in compassion and mindfulness, as well as the increasing use of MBIs in a range of populations, it is important that we understand these constructs further in terms of what they are and how they can be measured. To develop appropriate and suitable interventions, future research should return its focus to the theoretical understanding of these constructs. MBIs are based on the theoretical underpinning that mindfulness plays an important role in mental health (Williams et al., 2014); and now there is growing interest in the role of SC (Kuyken et al., 2010). However, in order for MBIs to be used appropriately, a sound theoretical and empirical knowledge of what is under investigation is necessary to understand how they may or may not be useful (Thompson & Waltz, 2007). Continued investigation into the extent to which mindfulness and SC are overlapping constructs seems justified, as well as exploring trait and state mindfulness and SC among differing populations who are potentially at increased risk for reduced wellbeing and poorer mental health.

Conclusion

This study builds on previous research exploring the benefits of SC and trait mindfulness to subjective wellbeing. In summary, the results of this study suggest that SC is a better predictor of parental subjective wellbeing than mindfulness, although this effect is small. As noted by previous research, the consolidation of a multi-faceted mindfulness measure into a single composite score may have impacted on the results and caution is advised when generalising to parents of CYP with T1D or other populations. Therefore, whilst SC may be a better predictor of parental subjective wellbeing when caring for a CYP with T1D, it is possible that the strength of the relationship with regards to mindfulness may depend on the conceptualisation of mindfulness and how it is being measured. It remains a key consideration that future research continues to explore the constructs of mindfulness and SC further before expanding the range of MBIs available.

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